Cris Kerr
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19th July 2016

Human Services inquiry
Productivity Commission
Locked Bag 2, Collins Street East
Melbourne Vic 8003

Dear Sir/Madam,

Re Submission - Human Services Inquiry – Public Health Services & Contestibility

I'm thankful for this opportunity to provide input of value to 'Human Services – Public Health Services and Contestibility', and approve publication of this submission in the public sphere.

This submission proposes a high-value solution that will provide a continuing legacy of enduring benefit to all Australians.

First, a little background:

Patient testimony has always been summarily dismissed by the scientific and medical communities and shown scan regard.

Though every patient's testimony contains information of value, their health and medical experiences are often labelled as *anecdote,* afforded no intrinsic scientific or medical value, and are never considered an aspect of reliable 'evidence'.

At present, patient testimony occurs as free-form text in an ad hoc fashion. This makes it difficult to qualify and quantify key data of value within testimonies.

Businesses involved in most industries have always been very keen to get feedback from their customers. Not surprisingly, most businesses seek to qualify their customers' experience and quantify their degree of satisfaction via structured collection of customer feedback.

Unfortunately, this cannot be said for the healthcare industry, as a whole, whether private or public.

Similarly, businesses have never had a problem qualifying the key points of customer feedback or quantifying their satisfaction levels. Again, this cannot be said of the healthcare industry.

Having always believed in the potential value of patient testimony to enhance health treatment and outcomes, I set up a community website in 2001 to collect health success stories. Every story submitted was entered into a database along with key words (diagnoses, symptoms, treatments). The purpose of the website was to share health success stories whilst progressing toward ‘proof of concept’ for the value of patient testimony.

During its period of operation (2001-2009), the ‘Case Health – Health Success Stories’ website amassed a significant number of stories attributing health success to an obscure treatment known as LDN (low doses of naltrexone).

I therefore perceived LDN to be the best opportunity available to achieve ‘proof of concept’ for the value of patient testimony, and focussed on this treatment in my final research publication; '*Those Who Suffer Much, Know Much'* 5th edition 2010.

(5)'*Those Who Suffer Much, Know Much',* 5th edition 2010, contains 51 LDN patient case studies supported by a collection of published scientific research and interviews with medical and other health professionals. It forms part of my submission and is available through the reference list included.

In the same year I edited a publication containing 201 health success stories attributed to LDN on behalf of the LDN Research Trust, UK; (6)'201 Reasons Why... You Should Know about LDN'.

Significantly, patients testifying they’d benefited from LDN were suffering a range of illnesses; from Multiple Sclerosis of varying stage, Primary Lateral Sclerosis, HIV, and Crohn’s Disease to many other conditions underpinned by immune system dysfunction.

At the outset, I believed Australia had systems in place to investigate the potential of this treatment in the best interests of patients, our health system, and our nation. I learned that was not the case, and is still not the case.

During, and in the ensuing years, I’ve shared this information with the NHMRC, Multiple Sclerosis Foundation, govt & political bodies, charitable, medical and scientific entities and individuals - too numerous to mention in totality; with the same result on every occasion – complete silence.

Initially, I couldn’t understand why Australia’s health and medical research environment or communities would not jump at the opportunity to conduct a clinical trial with a cheap, safe, ‘out of patent’ drug that held so much potential to improve both the health of Australians and the national health budget (with Multiple Sclerosis drugs costing Australia tens of thousands per patient per annum).

Citing Australia’s preference for market-driven healthcare, one person directed me to contact a commercial drug company. If that drug company happened to be the company that owned the patent for an MS drug costing tens of thousands of dollars per annum, and; I had proposed a clinical trial for an out-of-patent drug costing around $55 per month... *what do you believe the most likely response would have been?*

Something was very wrong.

Clinical trials are very costly, and clearly, Australia does not have an appetite for conducting clinical trials in the best interest of Australians or the health budget.

There is, however; an alternative solution:

This again is something I have previously (2)(3)(4)proposed on numerous occasions through numerous avenues – also without response.

I propose a high-value solution that not only addresses this shameful human rights issue but will also benefit every one of the Committee's points of reference and deliver an enduring legacy of continuing benefit to all Australians.

The solution involves making minor adaptations to Australia's new eHealth system so that patients have sufficient capacity to self-report their health status and outcomes in structured ways.

Providing structure for patient testimonies will facilitate qualification, and; as records accumulate, numbers will reach a 'volume value' tipping point that facilitates their quantification.

And when patient testimony can be both qualified and quantified, it will achieve just recognition as data that has an intrinsic value as an aspect of reliable 'health outcomes evidence'.

Through implementing capacity for patients to self-report and update their health status and outcomes in structured ways within their own eHealth records, the federal govt would be providing a sound core foundation that facilitates Australia's capacity to;

(a) qualify and quantify every tax and consumer dollar spent on healthcare against the quality/success or otherwise of Australians' short and long-term health outcomes with far greater transparency;

(b) support improved primary healthcare through delivering health professionals evidence-based data at their fingertips in the field to aid well-informed, collaborative, and timely decision-making;

(c) provide statistical and other de-identified health data of the highest possible integrity to Australia's health and medical research community for comparative treatment effectiveness, curiosity-driven or other worthy forms of health and medical research), which collectively will;

(d) heighten Australia's capacity to enact successful preventative healthcare measures, improve health treatments and short and long-term health outcomes, minimize national spending, reign in healthcare inflation, and enhance national productivity measures, and;

(e) earn income from de-identified data that is so reliable and has such a high degree of integrity that it would also be of 'long-term planning value' to every science and economic discipline, every business, govt dept, non-govt provider, etc across Australia and the rest of the world (through provision of planning data they can take to the bank).

Health professionals have called for heightened use of evidence-based medicine. This solution could deliver that in the form of de-identified statistical data to every health professional's desktop.

Health and medical researchers have struggled to provide sufficient evidence in their grant applications to support the need for, or potential of their proposed research, or to justify national research priorities. This solution also delivers on that objective.

We fear our prized public healthcare systems are not sustainable long term. Unlike the 'affordability' budget cuts recently proposed, this solution will deliver enhanced 'sustainability' year-on-year across multiple health budget platforms.

Consumers have been subjected to treatments that harm (adverse side effects, avoidable hospitalisations, and various other misadventures too numerous to mention) due to insufficient monitoring. This solution will aid 'red flag' monitoring and fulfil the ever-constant call for post-marketing surveillance.

Vested bodies have called for health systems to be more patient / consumer-centred. This solution will deliver on that objective within an environment that cannot be plagued by interference from vested interests.

We must address health system sustainability now, or it will continue to suffer successive budget cuts in every year ahead, but all proposals to date point to the preferred adoption of a US style health system which is demonstrably inequitable and of poorer quality than what we have now.

Australia should move quickly to adapt the national personal eHealth record to give patients the capacity to contribute comprehensive, structured, and timely feedback within their own eHealth records, and;

Australia should develop a robust publicly-owned framework that secures, maintains, manages, and protects the data integrity and individual privacy of all eHealth records within this publicly-owned framework, suitably chartered, to ensure it continues to serve the nation's and population's best long-term interests, and; to safeguard this highly sensitive, invaluable national data depository from being used for any other purpose than it's intended purpose, i.e; to ***improve the long-term quality of life and health outcomes of all Australians and sustain our highly-valued public healthcare systems.***

Australia can foster a continuous cycle of measurable improvement in public health, medical, and research outcomes by prioritizing and directing national public health and medical research funding to where it can contribute the greatest return value through;

- improving long term quality and sustainability of life, to;
- minimizing unnecessary suffering, and;

- fulfilling unmet public health and medical research needs;

to enhance national productivity and economic sustainability of government subsidized health and medical research, treatment and care.

Australia should also legislate to ensure this system can never be subjected to risks associated with individual or commercial vested interests locally or internationally, or similar (1)potential conflicts-of-interest, including but not limited to; lobbying and other related adverse activities and influences, off-shoring, out-storing or out-sourcing any part of this solution.

Whilst this reform will require initial investment of expertise and funds, expert economic analysis of this proposed reform will reveal its true potential and provide sufficient economic justification to proceed.

This proposal also delivers on other stated government objectives, that is; it would fulfil gaps in foundational support for innovation and contribute to product development and export growth goals.

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I remain hopeful of receiving confirmation of receipt, as well as a report on the outcome that includes this reform option as one that has the most potential to resolve collective objectives, as well as alleviate Australians' justifiable concerns regarding the increasing fragility of their highly valued publicly subsidized healthcare systems and subsequently; their healthcare futures.

This proposal, including all references, contains details of the only reform that can be fully justified and effectively implemented at minimal cost for major public benefit, including a high return on investment with significant reduction across associated 'conflict of interest' risks to all Australians' Healthcare futures.

Australians deserve nothing less.

Sincerely,

Cris Kerr

Volunteer Advocate for the value of patient testimony

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My Profile - 'The Conversation':
http://theconversation.com/profiles/cris-kerr-4564

Attachment:

Australian Atlas of Healthcare Variation - Cris Kerr Response, updated 16.7.16

References/Submissions:

1. SUBMISSION: 'Senate Inquiry into Out-of-pocket costs in Australian healthcare', No 105; Ms Cris Kerr, August 2014
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3. SUBMISSION: 'Feedback on the Draft Concept of Operations Relating to the introduction of a Personally Controlled Electronic Health Record (PCEHR) System', submitted 31 May 2011.
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4. SUBMISSION: 'Response to Community Affairs Committee Inquiry into Australia’s Personally Controlled Electronic Health Record (PCEHR) Bill', Submission No. 35, Cris Kerr, submitted 8 January 2012.
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RESEARCH:

eBOOK: 'Those Who Suffer Much, Know Much' 5th ed 2010 - 51 x low dose naltrexone (LDN) Case Studies, Prof Interviews, & Supporting Research/Studies; Cris Kerr, Case Health (Proof-of-Concept Research publication)
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Ex Administrator - 'Case Health - Health Success Stories' website
(May 2001 to May 2009 - casehealth.com.au & casehealth.com)